The informational needs of the newly diagnosed person with Multiple Sclerosis and their family.

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Abstract

The aim of the study was to identify from people with MS and their families, what information, in what format and when in the course of the disease they felt would assist the newly diagnosed person with MS and their family. A state wide cross sectional self-report study design was utilised for this research project. Thirty-four people with MS and 18 family members participated in the research proper. Participants self selected.

The people with MS and family and friends who participated in this research wish to be provided with a range of information. They recommended that the newly diagnosed and their families be provided with information that reflects their personal needs, be provided in person in both group and individual sessions and include research aimed at cures and therapies, counselling and support services early in the course of the disease.

Literature review

Access of timely, useful and informative information is integral to one's ability to play an active, collaborative and meaningful role in decisions. Without this information, people, particularly those with a chronic disease and their families, are handicapped when making decisions relating to their health and lifestyle.

Multiple sclerosis is a chronic degenerative disease of the brain and spinal cord generally diagnosed in people between the ages of 20-50 [1]. People with chronic diseases seek information to enable themselves to make sense of their situation, solve a problem or make informed decisions following the recognition of a gap in their knowledge or understanding [2]. These information-seeking behaviours made in response to a specific need represent an attempt to maintain some control over their lives. This is vital for people with long term disability or illness [3].

The informational needs of people with MS and their families has not received wide international coverage [4] to date. In 1994 Gulick identified that little informational support was available to people with MS which was surprising as the manifestations of MS frequently occur over the long trajectory of the disease. In 1996, Gregory, Disler and Firth, discovered that while people with MS found generic information regarding MS readily available, they found practical information at a local level frequently difficult to obtain.

Not only are peoples informational needs different, each person's response is likely to be either information seeking or information blocking [2]. Reasons suggested for the variation in information seeking behaviours are: fear of the unknown, fear of frightening oneself [5] and fear of discovering distressing information [2]. Gulick [6] discovered that many people with MS, once they realised there was no known cause or cure for MS believed there was little that more information can do to alter their situation. As the disease progressed, however, they developed new informational needs in response to either new symptoms or progressive deterioration of current symptoms.

The aim of the study was to identify from people with MS and their families, what information, in what format and when in the course of the disease they felt would assist the newly diagnosed person with MS and their family.

Method

A non-random purposeful sample was used to gain insight into the needs of this particular group of people. Thirty-four people with MS and 18 family members participated in this study. Participants self selected and were informed about the study through a variety of mediums: community newspapers, 'Forum' newsletter for People with MS, and people with MS support groups.

Eligible participants were 18 years or older, able to read and write English and able to complete the questionnaire. Each participant gave consent on his or her own behalf. The university where the researchers are based granted ethical approval.

Instrument Development

Two survey instruments were developed specifically for this study, one for people with MS and one for their family and friends.

The people with MS questionnaire included: demographic data and items determining the length of time since diagnosis of MS, level of disability at diagnosis and usual support network. In addition the questionnaire addressed the type of information about MS and services that would have been most useful at the time of diagnosis, format of this information, when it would have been most helpful to receive it, and to whom information about MS should have been offered, and by whom. Other items addressed included where information sessions should have been provided and at what time of day.

The family and friends of people with MS questionnaire contained similar items with the exception of the item identifying level of disability.

Study Design

A state wide cross sectional self-report study design was utilised for this research project. A pilot study was conducted with 9 people with MS and 8 family members or friends of people with MS was conducted to establish the validity of the survey instrument. Opinions were elicited about the relevance of the questions in general, the relevance of the questions to the participants, and any suggestions they may have for other important issues not covered by the questionnaire.

Thirty-four people with MS and 18 family members or friends of people with MS

participated in the main study. To enrich the data the chief investigator interviewed 7 People with MS and 5 family members of people with MS.

Results

Twenty-three women and 11 men with MS participated in the research. They were aged between 38-81 years. The average time between first symptoms and diagnosis was 9.5 years. Fifty percent of the people with MS were not working due to MS and twenty percent were retired. The sample reflected a group where only 14.7% were in paid employment.

Eighteen family and friends of people with MS participated in the research. Sixteen were aged between 40 and 69 years and two participants were aged 25 years or less, both being children of the person with MS. The majority of participants (81%) were spouse or partner of the person with MS.

Quantitative Findings

Participants recalled MS had adversely affected walking (79%), handwriting (65%), vision (46%), memory (53%) and mood changes (68%) early after diagnosis. In addition 38% of participants stated that their MS had resulted in the use of pads for urinary difficulties at the time of diagnosis.

When asked what information participants felt people with MS would find useful at diagnosis the responses included information about how MS would affect them (73%), managing MS (57%) and treatment for MS (50%). Family and friends indicated information on how MS would affect the person with MS (83%) and treatment and MS (67%) would be useful for the newly diagnosed persons' family. Views expressed by 50 % or more of the participants is presented in Table 1.

Table 1 Information that should be provided to the newly diagnosed and their families.

Recommended information	Responses from people with MS		Responses from family and friends	
	n	%	n	%
How MS may affect the person with MS	**25**	**73**	**15**	**83**
Managing MS	**19**	**57**	6	35
Treatment of MS	**17**	**50**	**12**	**67**

The participants were asked to identify those services that they would have liked to receive information about at the time of diagnosis. Responses from people with MS indicated that information about counselling (62%), People with MS support groups (59%), Multiple Sclerosis Society (58%) and physiotherapy and home exercises (56%) would be useful. Family and friends made very similar responses. Those items recommended by at least half the participants are presented in Table 2.

Table 2 Services that the newly diagnosed should have information about.

Recommended information about services	**Responses from people with MS**		**Responses from family and Friends**	
	n = 34	%	n = 18	%
Counselling services	**21**	**62**	**11**	**61**
People with MS support groups	**20**	**59**	**12**	**67**
MS Q information services and library	**23**	**58**	**12**	**67**
Physiotherapy and home exercises	**19**	**56**	**10**	**56**

When asked who should be told of the diagnosis people with MS felt that they should be provided with information (70%), and that their spouses (82%) and other family members (62%) should be told. They also stated that employers (68%) and young children (80%) should not be told about a person's diagnosis. Family and friends recommended that the person with MS (83%) and their spouse or partner (67%) be provided with information about MS and agreed that information should not be provided to employers (78%), young children (72%), older children (72%) or parents (61%).

Neurologists (88%), the MS Society (65%) and General Practitioners (62%) were identified as preferred sources of information about MS by people with MS. Only 33% of family and friends were in favour of the General Practitioner providing the information whereas over 67% wanted the neurologist to provide the information.

The neurologists' rooms were the most popular location (85%) for information sharing followed by the General Practitioner's rooms (65%), the local People with MS group (59%) and at the Multiple Sclerosis Society (50%). The local hospital, library and their own homes were not recommended for information sessions. There was no consensus about the time of day or day of week for these sessions.

The format that information should be provided in was also sought. Table 3 displays responses that 50% or more of the respondents agreed with.

Table 3 The format that information should be provided in.

Recommended format for information	**Responses from people with MS**		**Responses from family and friends**	
	n = 34	%	n = 18	%
One-on-one information sessions	**23**	**68**	**9**	**50**
Group information sessions	**21**	**62**	**12**	**67**
Pamphlets	**19**	**56**	5	28
Books	**18**	**53**	**9**	**50**

The preferred format for information sharing were one-on-one sessions (68%), group sessions (62%), pamphlets (56%) and books (53%). Respondents indicated that the radio, telephone, television, scientific papers, and the Internet were not the preferred format for gaining information about MS. Videos were recommended by 44% of family members as a preferred format of providing information.

Qualitative responses written on the surveys

The participants were given opportunity to write unstructured responses to four questions. The prompt questions included 'Think back to when you were newly diagnosed. The most helpful information I received was…, I feel the information should be provided as (indicate format eg talk, book, pamphlet)…, I think the best person to provide information is… and finally the information about MS I would like to receive now is...'

In response to the question focusing on helpful information, 22 people with MS responded. Twenty percent indicated that they had received no useful information at diagnosis, 17% were advised to contact the Multiple Sclerosis Society with a further 10% advised to contact Multiple Sclerosis Society at some later date.

When asked to indicate a favoured format of information 24 people with MS responded indicating 35% want the opportunity to talk with someone about the MS. This was followed by 16% suggesting books and 14% pamphlets.

When asked who should provide information the responses confirmed the earlier findings. Twenty-seven people with MS favoured their neurologist (21%) providing

information, 20% General Practitioner and finally 13% suggesting a person with MS also provide information.

Participants were asked to state if there was any information they would like now. Twenty-four people responded with requests for information about research aimed at a cure (46%), treatment medication advice (13%) and information about the MS Newsletter and the Multiple Sclerosis Society (8%).

Family and friends were also asked to respond to the same questions. In response to the prompt 'What useful information did they receive when their family member was diagnosed with MS?' the 10 responses indicated that 3 people were advised to contact Multiple Sclerosis Queensland. A further two participants stating they received no useful information at the time of diagnosis.??numbers

When asked about the preferred format of information 11 family and friends responded indicating that 3 participants preferred pamphlets, and 2 preferred videos, group discussions and one-on-one discussions. Numbers??

When asked who was the best person to provide information neurologists and General Practitioners were the preferred option.

Current information requested by family members included information about research (58%), a cure (25%) and new therapies (25%) reflecting the views of people with MS.

Qualitative interviews

In order to gain additional insights into the informational needs of people with MS and their families in-depth interviews were undertaken with both people with MS and family and friends by the chief researcher.

Seven people with MS participated in in-depth interviews lasting between 40 and 90 minutes. The interviews were all held in the participants' homes.

In response to the question 'What information would be helpful for the newly diagnosed? the participants indicated that more information about MS, the usual course of the disease and what to expect in the way of symptoms was required by the newly diagnosed.

Sources of information on MS utilised included written information in the form of pamphlets and brochures and specialist personnel such as Multiple Sclerosis Society staff. The implications was that specialist sources of information are necessary.

When asked who had provided them with information there were two clear groups; doctors and the Multiple Sclerosis Society.

The recommended format for information provision was dominated by the request for opportunities to discuss MS with someone. Newly diagnosed seminars, group sessions and individual counselling were very popular formats for seeking information. One person interviewed mentioned using the Web as a source of information.

An unexpected outcome of the in-depth interviews was the repeated comments about the impact of receiving information about MS. Many people with MS were shocked and dismayed by what they found but still felt they needed to be informed.

Five family and friends of people with MS participated in in-depth interviews. The responses of family and friends to the same questions were sought. This information was sought in order to gain insight into the needs of family and friends of people with MS.

In response to the question what information was / would be helpful? The responses identified the need for individualised information. Family and friends wanted answers to questions about the impact of MS and why some people were more affected than others.

Doctors were the primary source for most people gaining information about MS. Group sessions about MS were recommended as a strategy for providing information. The impact of receiving information about MS was mentioned again and the stress of this was mentioned again.

Discussion

The provision of accurate, relevant and timely information to the newly diagnosed person with MS and their family is an essential management strategy [7]. Individuals vary in their information seeking behaviours, none-the-less ‘when information and options are provided sensitively and in a way that will be readily understood, most people will choose to take responsibility for their health’ [8]. This research supports this view with all participants suggesting more information about MS be made

available to newly diagnosed person with MS. The need to individualise information and the option of discussing information with specialist health professionals were also strong recommendations identified in the course of the research.

The recent release of disease-modifying therapies in the form of interferon beta 1a, interferon beta 1b and glatiramer acetate for people with relapsing remitting MS has given hope to many people with MS. While Gulick's paper in 1994 [6] stated that many people with MS, once they realised there was no cause or cure for MS believed there is little that more information could do to alter their situation. This has now been turned around for people eligible to receive these disease-modifying drugs. These new therapies have resulted in people with MS and their families recommending that information about drug therapies be made available to the newly diagnosed.

Not only does information help people make sense of their world and sustain hope it also promotes self-determination. The promotion of independence and self-determination is the 'greatest service possible to individuals with severe disabilities' [9]. The ability to seek information helps people solve a problem or make an informed decision [2]. Participants of this research identified the need for more information to be provided to the newly diagnosed about the Multiple Sclerosis Society and its library, counselling, physiotherapy and support services.

The Internet is a source of current information across a huge range of issues including heart disease, physical training regimes [8] and multiple sclerosis. The Internet has the potential to provide a huge amount of information – but only to those with access, computer literacy or the finances to achieve both.

People with MS and their families wanted more information to be provided to the newly diagnosed. The research participants recommended that people with MS and their families have opportunity to discuss MS. While generic information is readily available [10] responding to individual information needs requires personal contact. Group information sessions and one-on-one sessions were requested repeatedly by the research participants. While it may be suggested that this sample, with a mean age of 59, may not reflect the wealth, computer literacy or Internet skills of younger people with MS, the point remains the Internet does not provide the personal contact requested by these people with MS and their families.

This personal element of the health professional / consumer relationship may be the

preferred option but access may present a formidable barrier. While access to information is well recognised as an important element in the provision of health care [11] knowing where and how to access information is also a significant factor in finding information. The research participants suggested that the neurologist and General Practitioner were the preferred sources of information about MS. The preferred location was the neurologist's rooms, their General Practitioner's rooms or the Multiple Sclerosis Society.

While neurologists and General Practitioner may be in the best position to offer information about MS their ability to address day-to-day issues has been questioned over the last ten years [12];[13]. The criticisms are that doctors are not knowledgeable about difficulties with daily living, social security benefits or other entitlements [12]; [13]. This being the case, people with MS and their families need to be made aware of other sources of information.

The research participants stated that the Multiple Sclerosis Society was able to provide such information, as were MS support groups. The concern is that only 17% of the participants were advised to seek out the Multiple Sclerosis Society at diagnosis with a further 10% advised to 'at some later date'. This leaves 73% of newly diagnosed people with MS left to their own devises to find information they need. Since the provision of timely, accurate and helpful information is empowering, the withholding of such information is equally disabling.

At the time of diagnosis people with MS look for information about MS and the social impact of the disease. Practical information becomes more important later on. While it is true that not all people with MS seek information [2] health professionals place themselves in a gate-keeping role that may not be in the best interests of the person with MS by withholding the details of where information can be sought.

In summary the people with MS and family and friends who participated in this research wish to be provided with a range of information. They wanted information that reflected their personal needs, provided in person in both group and individual sessions and to receive information about research aimed at cures and therapies, counselling and support services early in the course of the disease.

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Acknowledgments

People with MS

Friends and family of people with MS

Multiple Sclerosis Queensland

Queensland Nursing Council